What is a minimally conscious state?

In recent decades, modern medical technology and resuscitation techniques have produced new neurologic syndromes of severe, and usually irreversible, cognitive and motor disabilities. The three most significant and most common of these syndromes are brain death, vegetative state, and locked-in state. Consensus panels of medical societies have addressed the medical and neurologic aspects of these syndromes, including definitions and essential clinical characteristics. Many landmark right-to-die cases have been tested in the courts and widely publicized, and multidisciplinary groups have attempted to develop ethical and legal guidelines for these problematic cases. ²

The vegetative state is probably the best known of these new syndromes. Patients in a vegetative state are awake but unaware. They have sleep/wake cycles with eyes open for prolonged periods but show no evidence of consciousness on physical examination. The vegetative state becomes permanent at 3 months for patients with anoxicischemic injuries of the brain and after 12 months for those with traumatic injuries. The chance of any meaningful recovery of neurologic functions after these periods of time is extraordinarily rare.

But many medical and ethical controversies still surround the vegetative state. Physicians have noted an unacceptably high rate of both false-positive (patients were incorrectly diagnosed as being in a vegetative state when they had some evidence of consciousness) and false-

negative (patients were thought to have some degree of consciousness when, in fact, they were truly vegetative) diagnoses.³ Another problem has been the lack of any specific terminology to describe patients who emerge from the vegetative state to the next higher level of consciousness. Several right-to-die cases have involved patients who clearly were not vegetative but were otherwise severely neurologically disabled.

Because of these and other controversial issues, a multidisciplinary group of physicians developed a consensusbased definition of this new syndrome and medical criteria for its diagnosis (the Aspen Work Group).⁴ Previously described as the minimally responsive state, this new syndrome in which the patient emerges from the vegetative state to have some degree of cognitive function is more accurately labeled the minimally conscious state (MCS). The Wendland case illustrates the essential clinical features of MCS and would definitely fit the diagnostic criteria developed by the Aspen Work Group.^{5,6}

The Aspen Work Group defines MCS as "a condition of severely altered consciousness in which minimal, but definite, behavioral evidence of self or environmental awareness is demonstrated." Before rendering a diagnosis of MCS, the patient must demonstrate on physical examination one or more of four types of behaviors on a reproducible or sustained basis. These neurologic behavioral characteristics at the bedside are shown in the Box. The

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Behavioral criteria for the diagnosis of MCS*

Follows simple commands

- Gives yes or no responses verbally or with gestures
- Verbalizes intelligibly
- Demonstrates other purposeful behavior, including nonreflexive movements or affective gestures that occur in direct relationship to relevant environmental stimuli, eg:
 - appropriate smiling or crying in response to specific emotional stimuli
 - vocalization or gesturing in direct response to linguistic content of questions
 - directed reaching for objects that demonstrates a clear relationship between object location and direction of reach
 - modification of touch or grasp to accommodate the size and shapes of objects
 - pursuit eye movements or sustained vision fixation upon a external visual stimulus

most important and the one usually first seen when a patient emerges from a vegetative state into MCS is sustained visual pursuit.

Although MCS patients demonstrate cognitive behaviors to some extent (even though only minimal), they are similar to patients in the vegetative state in other important ways.⁷ Both are so severely impaired that they have severe immobility and are unable to perform any meaningful activities of daily living. They are unable to communicate meaningfully and have bladder and bowel incontinence. They require the use of a feeding tube but usually are able to breathe without a respirator. Patients in a vegetative state, however, are unconscious and therefore have no awareness of self or environment and show no evidence whatsoever of language comprehension. They do not experience pain and suffering. MCS patients, while severely impaired in terms of consciousness, have some definite, but extremely limited, awareness of self or environment, and limited means of communication. They are able to experience pain and suffering to some degree, although often the actual degree of pain and suffering cannot be determined.8

From a neurologic standpoint, MCS patients are thought to function at the level of a patient with severe or, more accurately, profound dementia. According to the Aspen Work Group, the estimated number of MCS patients in the United States is 112,000 to 180,000 compared with previous estimates of 14,000 to 35,000 patients in the vegetative state.

MCS patients can be separated into three groups based on the nature of their disease or injury

- Developmental or congenital injuries to the brain occurring before or at birth, eg profound mental retardation
- Acquired traumatic or nontraumatic injuries to the brain, eg severe head injuries

 Progressive degenerative disease of the central nervous system, eg Alzheimer disease in the end stage

Use of the term MCS does not necessarily imply permanence or irreversibility of the disease process. Patients emerging into MCS after weeks or months in a vegetative state caused by a traumatic head injury may continue to recover and do well, regaining further significant neurologic functions over a period of months or years. A less favorable prognosis for further recovery can be expected for those MCS patients with end-stage Alzheimer disease, profound mental retardation, or stable acquired traumatic injury to the brain after 1 year.

The ethical and legal implications of a potentially *transient* state are different from similar considerations for a *permanent* MCS.⁹ Because our knowledge of MCS is more limited than that of the vegetative state, we cannot say with any degree of certainty at what point after injury to the brain (either nontraumatic or traumatic) the condition becomes permanent. Although the Aspen Work Group noted that meaningful, good recovery after 1 year in an MCS is unlikely, more data are needed to confirm the criteria for and timing of realistic prognosis for recovery.

Just as the first quarter-century of the right-to-die movement may be exemplified by the medical, legal, and ethical assessments of brain death and the vegetative state, so the first quarter century of the new millennium may be the era of patients who are substantially neurologically impaired but conscious to a variable degree. Perhaps MCS will capture the essence of this next wave.

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^{*}At least one is required for diagnosis